

Department of Mental Retardation
Annual Family Support Plan
State Fiscal Year 2004 (July 2003 – June 2004)

Background

Since 1995 the Department of Mental Retardation (DMR) has been providing flexible family support services. In July 2002, Chapter 171 of the Acts of 2002, “An Act Providing Support to Individuals with Disabilities and Their Families,” was signed into law. This legislation specifies that all named state agencies, with substantial consultation from individuals with disabilities and their families, need to prepare and submit on an annual basis an individual and family support plan that explains how the department intends to provide flexible supports to families and individuals. This is the Department of Mental Retardation’s first Annual Family Support Plan.

Overview of Family Support

Definition of family support:

Family support strives to achieve the goal of helping families stay together through:

- Developing the family’s natural capacity to meet the needs of family members;
- Offering additional supports such as staff resources, goods and services, and financial assistance; and
- Enhancing the capacity of communities to value and support people with disabilities and their families.

Array of family support services and how funding will be used to deliver these services through network of family support providers:

Approximately **\$37 million dollars** was spent on a range of family support services in Fiscal Year 2003, (July 1, 2002 through June 30, 2003). Approximately **\$28.8 million dollars** of this total amount provides funding for general family support services, which includes the required Core Service Elements and flexible funding allocations. The rest of this funding is used to fund a variety of enhanced and specialty family support services. Every DMR region funds Enhanced Family Support services including *Intensive Family Support* and *Medically Fragile Projects*. In addition, each DMR region has funding for an *Autism Support Center*. Also, there is funding for a variety of specialty family support projects that vary from region to region, such as after-school programs, social/recreational activities, camps, and planned facility-based respite services. Some of these services are designed to provide services for children only.

The Department of Education & Department of Mental Retardation Community Residential Education Project is a collaborative initiative that had an allocation of \$7.5 million dollars in fiscal year 2003. During fiscal year 2003, 288 children participated in this project. This included 29 students who were assisted to return from residential school placements to their home communities. In addition, 259 students utilized project resources to obtain a diversity of supports as an alternative to an initial residential special education school placement.

It is estimated that approximately **10,000 to 13,000 families** across the lifespan are receiving some type of family support service at any given time. These services are delivered through contracts developed with about **74** family support provider agencies across the state. All Family Support Provider Agencies are required to complete and evaluated on **Performance Outcome Measures** that are designed around the key principles and core service elements for family support.

In July 2002, the Department issued the *New Family Support Guidelines and Procedures*. This is a document that describes the goals and principles of family support, the core service elements to be offered and other supports available, and all of the operational requirements. This document was first published in 1995 and most recently revised in July 2002.

DMR internal family support network:

Presently DMR is organized into five regions with Regional Directors, and 24 Area Offices with Area Directors, all under the umbrella of Central Office. By the middle of this fiscal year the Department will be reorganized into 4 regions with 23 Area Offices. Each DMR region has a Director of Family Support Services. In each Area Office there is a Children's Coordinator who generally works with children under the age of 18 years and their families, and a Transition Coordinator who works with individuals generally between the ages of 18 and 22. Adults over the age of 22 who have met the eligibility criteria for DMR services are assigned a Service Coordinator and participate in an Individual Service Planning process.

Process for obtaining "substantial" input from families regarding current family support services:

The Department used several approaches to get input from family members to help assess the Department's current system of family support and to help craft this Annual Family Support Plan. One approach involved hosting forums with family members that were held across the five regions of the state in December 2002 – January 2003 in partnership with Massachusetts Families Organizing for Change (MFOFC). These forums provided the opportunity to get direct, face-to-face input from families about the strengths and gaps in our current system of family support. The results of these forums are described in a separate report and were used in the development of this plan. A second approach involved the administration of a mail survey to family members regarding their opinions of the services and supports for children with disabilities and their families. We have also conducted a parallel survey with families of adults who reside in the family home. Both of these activities are part of the "National Core Indicator Project" that DMR participates in along with twenty-two other states. The survey for families of children with disabilities was sent to approximately 1500 randomly selected families from across the state, who have a child under the age of 18 and who are receiving family support services. These results will also be used to guide priorities for the annual family support plan.

Focus Areas

- I. Family Empowerment:** Opportunities for families and individuals to be involved in the development of agency policies and procedures, program development, and evaluation of services.

Current Activities:

1. The Department, in partnership with MFOFC, hosted five regional forums for family members in December 2002 – January 2003 to gather assessment information on current strengths of the agency's family support system and to identify gaps and concerns. This information helped inform the development of this Plan.
2. The Department has initiated family-governed and family-directed projects across the state to enable families to exercise increasing control and influence over the direction and operation of these family support services. Information about these initiatives is included in the Department's "Family Support Guidelines and Procedures."

3. Through goal setting and monitoring, Department staff will work with Family Support Provider Agencies to improve their performance in meeting contractual requirements and Performance Outcome Measures, with a particular emphasis on the following expectations: to provide opportunities for the establishment of family councils; to get family member input on policies and program development; and to at least annually conduct satisfaction surveys with families to get information about supports provided and ways to enhance services for families.
4. The Department has convened ad-hoc groups of family members at different times to get specific feedback and input on program development and policy changes and initiatives; Examples include: revisions to the Family Support Guidelines and Procedures, the development of the Family Support Request for Response, and planning activities regarding the Home and Community Based Waiver for Children.

New Initiatives:

1. The Department will establish a Statewide Family Support Council representative of the geographic, cultural, ethnic, and linguistic diversity of families in Massachusetts. Its primary purposes will be to advise the Department on issues that affect the well-being of families with family members who are either living at home or have recently transitioned from their home, and to be an important vehicle to receive “substantial consultation” from families in crafting and implementing the Department’s Annual Family Support Plan. It will be important for representatives on the Statewide Council to be in touch with the “grassroots” so that it maintains its independence and integrity. The Department will set aside some funding to pay for some of the costs necessary for family participation, such as respite, transportation, translation, etc.
2. The Department will host a variety of regular and well-publicized local and regional forums for feedback on service delivery and program development needs, including but not limited to town meetings, small focus groups, information-sharing sessions, etc. These forums will provide input to be used in the development of the Annual Family Support Plan and to also determine satisfaction with activities outlined in the Plan.

II. Family Leadership

Current Activities:

1. The Department provides support for family-directed groups to provide educational and leadership opportunities for families, such as the Family Leadership Series sponsored by MFOFC.
2. As part of the Core Service Elements, Family Support Provider Agencies are expected to provide and offer varied educational and learning opportunities for families and individuals that are responsive to their specific interests and needs.
3. In partnership between the Department and the Arc, fifteen Family-to-Family Support Centers provide a range of educational and training opportunities on a range of topics, as well as mentoring and clinical support services to families covered under the Boulet Settlement Agreement, to help them develop more independent living options for their family member. These services also help develop a network among families for ongoing support and assistance.

New Initiatives:

1. The Department will provide funding for leadership development opportunities for families in all of the DMR regions.

2. Department staff will explore with family members the types of support and assistance that may be helpful to them as they plan for and encourage more independent lifestyles with their adult son or daughter, including moving out of the family home. One avenue of exploration will involve the resources of the existing Family to Family Centers mentioned above.

III. Family Support Resources and Funding

Current Activities:

1. The Department will continue flexibility in funding options to support individuals and families.
2. The Department will continue funding for enhanced and specialized services in order to respond to the specific needs of individuals and families, e.g. the Medically Fragile Projects, the Intensive Flexible Family Support Services.

New Initiatives:

1. The “Family Support Guidelines and Procedures” will be updated to ensure that departmental funding mechanisms and policies and procedures support flexibility in services to eligible individuals and their families. When finalized, Department staff will implement a variety of ways to disseminate these and offer training on the key changes to both DMR staff and provider agencies, creating an opportunity to also address improved consistency in how services are provided across the state.
2. The Department will pursue federal reimbursement for family support services through the development and approval of a Home and Community Based Waiver for Children.
3. The Department will develop a variety of ways to share information and support families and their adult family member in exploring and pursuing more flexible, consumer and family driven approaches in the design and purchasing of support services. Some of these approaches include, but are not limited to, funding partnerships between families and DMR, self-determination initiatives, and expanded utilization of an Intermediary Service Organization (ISO). This information may be most applicable to individuals in the process of transitioning from school to adult life and their families, and outreach efforts will initially be focused on reaching this group.

IV. Accessing Services and Supports

Current Activities:

1. The Department has developed a website for the agency and will work to enhance the family support information on the website to be more helpful to families.
2. The Department, in partnership with other groups, offers a variety of ways for families to access information about services and resources, such as, New England Index, MassCares, First Call (United Way), etc. The Department will work to improve publicity and information about these resources to help make sure families are aware of and can access them.

New Initiatives:

1. Each DMR region will develop and make available Family Support resource information that provides both a comprehensive listing of the Family Support Provider Agencies in their region, and contact information for other family support organizations and resources both in their region and statewide. This information will be developed to be responsive to the primary cultural, ethnic and linguistic backgrounds of families in each region.

2. The Department will develop a “Family Support Handbook” that will be an abridged version of key sections of the Family Support Guidelines and Procedures that is of greatest importance and relevance to families in using family support services.

V. Culturally Competent Outreach and Support

Current Activities:

1. The Department will continue to support a number of existing cultural initiatives in western Massachusetts and with the Family Governing Boards in Boston representing different cultural and linguistic communities, as well as focused outreach and family support initiatives in many other areas and regions.
2. The Department has established a Diversity Council and has a Diversity Plan that includes a focus on staff training on diversity and more culturally competent service delivery.

New Initiatives:

1. The Department will develop a comprehensive and streamlined system for the translation of DMR information and materials and the provision of interpretation services, in order to promote the delivery of culturally competent family support services.
2. As part of the Core Service Elements, Family Support Provider Agencies are expected to respond to the specific ethnic, cultural and linguistic needs of families in the geographic area that they serve. DMR staff will utilize the performance outcome monitoring process to evaluate progress in this area and work with provider agencies to improve their cultural competence.
3. The Department will explore different grant opportunities and outreach initiatives to build upon and expand multi-cultural efforts and services, e.g. funding through the Administration on Developmental Disabilities, the Capacity Interchange Project at the Institute for Community Inclusion, etc...

VI. Interagency Collaboration

Current Activities:

1. The Department of Education and Department of Mental Retardation Community Residential/Education Project has been in operation since 1995. It is designed to assist individuals who are returning from residential school placements to their home communities, as well as provide supports that enable individuals to remain in their home communities to prevent residential school placement. During Fiscal year 2003 this project provided services to 282 individuals and their families with a funding level of 7.5 million dollars.
2. The Department is involved in a number of inter-agency activities with other EOHHS agencies as well as other state agencies to enhance service delivery to families and individuals served by both agencies. Examples include the Elder Caregiver Project, the Interim Policy with the Department of Social Services, etc..

New Initiatives:

1. DMR will take the lead role in convening on a regular basis all the other state agencies named in this legislation to discuss progress on family support initiatives and to work collaboratively on improving and expanding family support services. In addition, all of these state agencies will participate in jointly sponsored, cross-agency forums for family members in the Spring of 2004 in order to get broader input about the needs and concerns of family

members, strengths of current family support services, and ideas on ways to respond to the gaps that exist.

2. The Department has received a one year federal grant from the Administration on Developmental Disabilities for the planning and design of a One Stop Family Center in the city of Springfield. This proposal includes a Memorandum of Understanding signed by all the disability agencies in addition to the Departments of Education and Department of Social Services, to work collaboratively in this planning effort and to identify ways to better coordinate and integrate information and services for families from diverse ethnic, racial and linguistic backgrounds who have a child or adult family member with a developmental disability.
3. In the Executive Office of Health and Human Services an Inter-Agency Group, the *Transition Team*, has been developed to establish a more streamlined approach for assigning state agency responsibility for service planning for individuals in the “Turning 22” process who “fall between the eligibility cracks.” The *Transition Team* includes representatives of the Departments of Mental Health, Mental Retardation and Social Services, and the Massachusetts Rehabilitation Commission, Massachusetts Commission for the Deaf and Hard of Hearing, and the Massachusetts Commission for the Blind.
4. Within EOHHS a number of specific committees and work groups are being established to identify ways to better serve families at risk.